

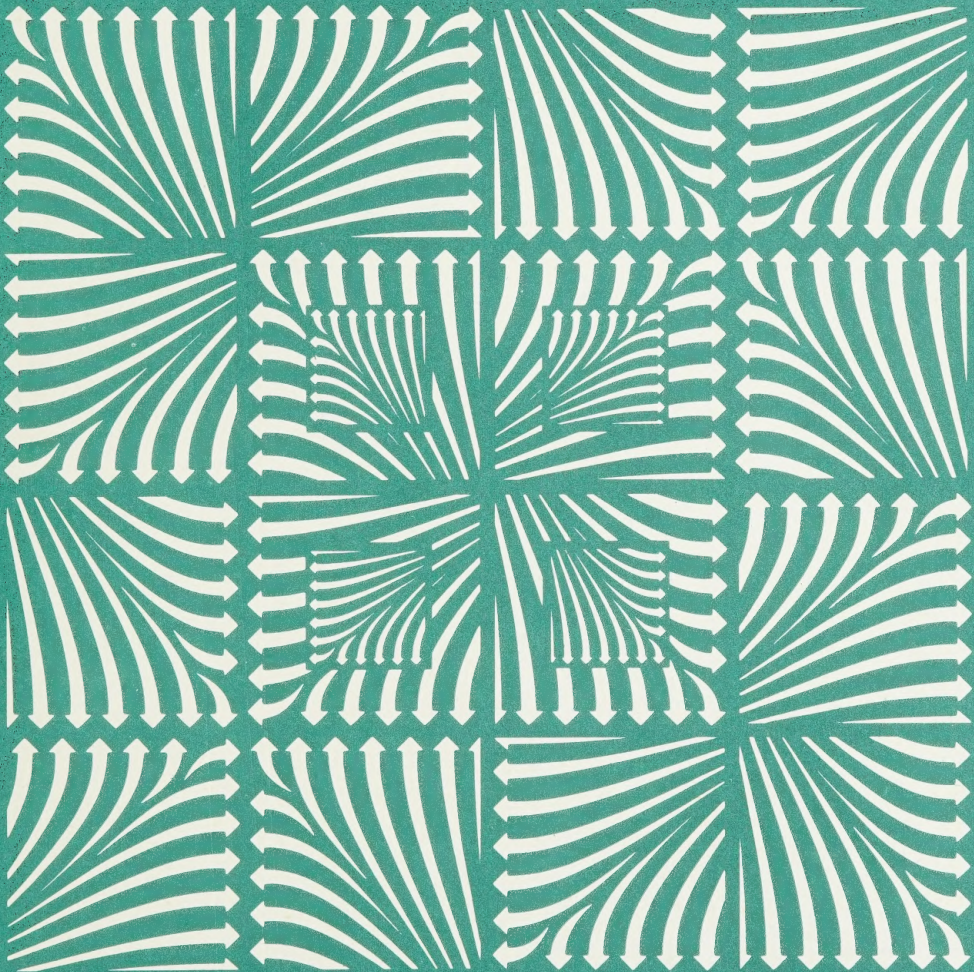
Report of the
Consultative Group
on Ethics
The Canada Council


Ethics

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Ethics

Report of the Consultative Group
on Ethics

The Canada Council 1977

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Foreword

With the recent growth of research involving human subjects, the Canada Council, as a board of public trustees, has become increasingly anxious to ensure that the research it supports is conducted according to ethical principles; for while these principles appear to be universally accepted, problems seem to arise out of the considerations brought to bear in their application. On more than one occasion, projects forwarded to us with the blessing of a university have given rise to concern on ethical grounds in our Advisory Academic Panel as well as among the members of Council itself.

For this reason we took the initiative of setting up a Consultative Group on Ethics, to advise us on the application of the general ethical principles which should be observed by researchers in the humanities and social sciences and on the role and composition of the review committees which should screen applications before they are forwarded to us.

We consider ourselves most fortunate that a group of distinguished scholars agreed to assume this difficult and delicate task. They are J.A. Corry (Kingston, Ontario) as Chairman of the Group; Michael Ames (Department of Anthropology, University of British Columbia); Anthony Doob (Department of Psychology, University of Toronto); Gilles Lalande (Director of the Centre d'Etudes et de Documentation, University of Montreal); Jan J. Loubser (Director, Social Science Research Council of Canada); Abbyann Lynch (Department of Philosophy, St. Michael's College, University of Toronto); Arthur M. Sullivan (Regional College, Corner Brook, Nfld.), observer from the Council's Advisory Academic Panel; and André Villeneuve (Department of Psychiatry, Laval University). Within their terms of reference they have been free to explore the subject in their own way and to come to their own conclusions. In this report, they have elaborated on the reasoning that led to their conclusions.

We are in complete agreement with the Group's recommendations that its report be given wide distribution within the academic community, and that reactions be invited. Based on these and on the Group's advice, the Council will formulate guidelines for use by applicants for research support.

It remains for me, on the Canada Council's behalf, to thank the members of the Consultative Group on Ethics for their willingness to accept this assignment and for the considerable time and effort they have devoted to their task over the past months. I should also like to thank the universities and learned societies for their helpful cooperation, without which it would have been impossible to carry out this study.

We hope that this report will stimulate discussion and interest in the academic community which will result in greater awareness of the need for vigilance with respect to the protection of human rights in humanities and social science research.

Charles Lussier
Director
The Canada Council

Terms of Reference

of the Consultative Group on Ethics
with Respect to Research Involving
the Use of Human Subjects

To advise on:

- 1) a common ethical code which institutions will be asked to apply before forwarding to the Canada Council applications involving the interests and legitimate concerns of human subjects;
- 2) the composition of the institutional committees reviewing such applications;
- 3) the procedures to be used by the institutional review committees.

I Introduction

Dilemma arising out of conflict of values

The task of advising on the ethical principles which should govern the conduct of research in the humanities and social sciences has not been an easy one, for inherent in the problems of this research is a conflict of values. It manifests itself in the dilemma faced by the researcher and any institutional review committee screening his application: how to strike a proper balance between respect for the rights and sensibilities of the individual or collectivity, on the one side, and society's need for advancement of knowledge on the other.

Need for research

Without some systematic probing of the unknown, scientific progress would not be possible. Such progress presupposes well-prepared professional researchers, gifted with vision and motivation, to extend the present limits of knowledge within their disciplines. In its tacit approval of research and its goals, society endorses the role played by the researcher and recognizes certain rights as his prerogative. However, as history has

Abuse of rights

illustrated, these rights tend to be abused, often because investigators are not aware that the research they plan to carry out involves serious social and ethical issues. In actual fact, whenever human beings or their intellectual or cultural properties are used in research, and whenever the legitimate interests and concerns of individuals or collectivities are affected in the cause of scientific advance, ethical issues must be considered.

The ethical principles

What are the ethical principles which should govern the conduct of research in the humanities and social sciences? While recognizing the vital importance of research to human progress, we affirm that consideration for the welfare and integrity of the individual or particular collectivity must prevail over the advancement of knowledge and the researcher's use of human subjects for that purpose. Given this premise, it follows that certain individual/collectivity 'rights' must be maintained, such as the right to be fully informed about the precise nature and purpose of the research in which participation is sought, so that consent may be given or withheld advisedly; the right to know of the risks and benefits involved in participation in the proposed research; the right to assurance that privacy will not be invaded and that any information disclosed will remain confidential; the rights of living members of a society regarding the entry of 'outsiders' to examine their burial grounds, to remove and store sacred and cultural objects

or to exhibit and dispose of these objects; the right of cultural groups to accurate and respectful description of their heritage and customs and to the discreet use of information on their daily lives and aspirations.

Such a listing is neither original nor exhaustive. Many of Canada's institutional and professional codes of ethics for research on human subjects make reference to these or similar individual/collectivity 'rights'. In so doing, they are unanimously sympathetic to our primary concern.

Existing codes

However, close examination of these codes reveals that almost all tend to withdraw with qualifications what they have asserted in principle, so that a researcher is provided with many reasons why he may, in the interests of science, compromise on ethical principles. He is thus left with few firm guidelines to determine whether or not it is wrong for him to do so. Moreover, no consideration is given in any of the university codes to the special problems faced by researchers working outside their own culture and little consideration to third-party risks.

Generally, no special mention is made of unforeseen damage, vulnerable populations, secondary use of data, remuneration of subjects, types of psychological damage and other forms of risk or types of invasions of privacy. There is often no consideration given to the desirability of using independent advocates for children or for captive populations. Little guidance is offered to the researcher or review committee and there is little or no discussion of the purposes of ethical review, the various aspects of the key issues involved, the trouble spots to look for or the question of where lies the burden of proof.

Need for guidelines

From our experience in conducting this enquiry we realize that it is clearly impossible to standardize procedures for implementation. We also realize that the ideal may not always be attainable. But we have tried to draw up guidelines to assist the researcher and the institutional review committee in minimizing any adverse effects of research involving human subjects, for it is our view that discretion in these and related areas of research cannot be left entirely to the researcher or the review committee. The too-frequent sanction of qualifications or exceptions to the protective principles on which research on human subjects is founded will inevitably lead to the erosion of the principles themselves. The very

antithesis of stated principle will become the rule, and society's right to knowledge will override the rights of the human subject.

Responsibilities of the Canada Council

We therefore recommend that the Canada Council, as a public trustee of the funds it dispenses, exercise the responsibility it bears for moral leadership by asking all institutions and agencies whose members apply for research support to re-examine their existing codes concerning human research and to draft codes where they do not exist, in either case bearing in mind the guidelines set out in this report. The professional associations should be asked to do likewise. We further recommend that the universities be asked to re-examine their review procedures and to set up institutional review committees, if they do not already exist, to screen applications for Research and Negotiated Grants and Leave Fellowships before they are forwarded to the Canada Council.

Responsibilities of universities and professional associations

We have no hesitation in making such recommendations because it is our conviction that the universities and professional associations ought to be especially concerned with the rights of those with whom their investigators work. As the community looks to them and to the agencies for academic leadership, it also expects that these organizations will assume the moral and legal responsibility for research conducted under their aegis. Indeed, in this particular area the research agencies, because of their special research involvement, bear the unique social responsibility for interpreting the community's ethical standards to the research sector. Who else can do so? The research agencies, universities, institutions and professional associations must demonstrate, as must their researchers, that the community sense of right will always be respected, even if some types of research must be abandoned. Inasmuch as society feels the need to protect the rights of its members, the investigator is obliged to respond to that aspect of the social conscience in carrying out his work.

Danger of ignoring community sense of right

The danger implicit in ignoring the community sense of right needs little emphasis, given the numerous examples cited of subject abuse and growing public concern about research costs. For what is now a socially approved and supported enterprise could all too easily become a matter of indifference to society, not to say a focus of active

social disapproval. Ultimately, funding as well as subject participation in research could dwindle, and society might well find what it considers to be other more urgent and worthy claims on resources than research with human subjects.

Need for frequent
review

We cannot over-emphasize the need for vigilance with respect to ethical issues in humanities and social science research involving human subjects, for enunciation of ethical principles will not of itself guarantee ethical practice. We see the Canada Council as having a responsibility for helping to develop heightened sensitivity to these issues. We therefore hope that the Council will see fit to make our report available to universities, museums and professional associations, and that they in turn will relay their reactions to the Council.

Summary

In preparing the report for the Canada Council, we have not been unaware that any comprehensive code of professional ethics for the humanities and social sciences would cover three areas: research, teaching and practice or therapy. In accordance with our mandate, however, we have restricted our concern to research carried out in pursuit of their scholarly interests by professional scholars recognized by academic institutions, disciplinary associations and granting agencies. We have attempted to offer guidance to researchers and institutional review committees on any procedure carried out by one person involving the person or privacy of another with the intention of advancing knowledge. By extension, we have also concerned ourselves with the examination and interpretation of records, artifacts and other significant cultural properties indigenous to the individuals or groups on whom research is being carried out.

Limitations of our
concern

We have tried to give particular attention to principle and implementation of principle and to express our concern that principle may be eroded in practice unless certain guidelines are clearly enunciated. In this connection, we have discussed some of the discretionary issues uniquely pertinent to research in the humanities and social sciences as well as the different types of research in which these issues might arise. The format of the report, an expression of right derived from principle, followed by guidelines for implementation, expresses our thinking on these issues. The need for stated principle is obvious, but co-requisite and no less imperative in our view is the need for guided flexibility in implementation.

II Research in the Humanities and Social Sciences Involving Human Subjects

General Comments

The widespread relevance of ethical principles

Ethics are involved in research undertaken by practitioners in a wide variety of disciplines, using many different methodologies. It is well known that psychological experimentation, sociological survey, educational testing and anthropological investigation all involve ethical issues, but it is less well recognized that the economist, linguist, demographer, political scientist and criminologist — even the historian, biographer and archaeologist — also gather data through direct and indirect contact with people and can have an impact on their lives. Their research is also of ethical concern. It is not therefore the discipline that determines the presence or absence of ethical considerations, but whether or not the methodology employed results in the research having a direct impact on human beings.

Limitations of the experimental model

Quite early in our work we realized that most codes of ethics had been developed for research involving 'experimentation with human subjects', following the model of the medical or psychological experiment. In this model, subjects, research procedures, anticipated effects, possible benefits and risks can be fairly clearly identified. The nature of the relationship between researcher and participants in the research is specific and the costs and benefits of involvement in the research are fairly readily identifiable. Procedures for obtaining informed consent and ensuring confidentiality and anonymity are equally specifiable and open to examination.

It was immediately obvious that this model of research had only limited applicability in the social sciences and humanities. Certainly, in psychology, education and some other disciplines the model applied quite directly to certain types of research. But research ethics, or guidelines on such ethics, fashioned on this model alone would clearly not be very helpful to most researchers in the majority of social sciences and humanities disciplines. We realized that our guidelines would have to be more comprehensive if they were to be of assistance to researchers in all the disciplines and to institutional review committees.

Alternative model

The principles and guidelines proposed herein are also meant to be useful to the survey researcher in sociology, political science, criminology or demography. They are intended to provide direction on ethical issues involved in the documentary research pursued by historians and

biographers. Archaeologists and anthropologists should find here ethical criteria for research involving cultural objects and property, the informal observation of people, interviewing them, or simply living among them and documenting their way of life, beliefs, habits and practices.

The ethical principles and guidelines suggested in this report, therefore, apply to the whole range of approaches and methodologies found in the social sciences and humanities where the research is likely to have some direct or indirect impact on human beings, their culture or their environment. They do not presume that research procedures can always be specified in one mode or that the potential impact of research using human subjects can be calculated in terms of costs and benefits. They do suggest that, even in the most diffuse research procedure such as casual observation, the researcher and the institutional review committee have the obligation to raise every ethical issue, to presume that every ethical principle applies and to accept the burden of proof that it does not or that the proposed procedure meets the ethical principles involved.

Ethical Principles

1. Informed Consent

The information to be given

The single most important device for resolving the dilemma between the need to respect the rights of the people participating in research and the need to provide for the advancement of knowledge is the procedure of informed consent — informing the potential participants of the nature of the research, the risks and benefits, and allowing them to decide for themselves whether or not they wish to participate.

It is axiomatic that no research involving humans should be undertaken without their freely-given, informed consent, if possible in writing, and that investigators should honour all commitments associated with such agreements. The information given to a subject should be complete and presented in a way which takes into consideration the level of his comprehension. An exact description should be provided of all aspects of the research project, its purpose, usefulness, expected benefits, methods, foreseeable effects, risks (including possible hazards to physical and psychological well-being and jeopardy of social position) and where appropriate, a description of alternative procedures which might be

used. It should be possible to assure subjects that the research in the form to which they are giving consent will be closely monitored. Subjects should always be apprised of any considerations which might lead them to refuse to participate. At the same time, an offer should be made to answer inquiries concerning the research. While the researcher will be the primary person responsible for answering such inquiries, he should whenever practicable be willing to suggest a second, knowledgeable person, other than a member of the research group, if the subject wishes further information and review concerning the proposed project.

Unknown risks

Since research by its very nature involves the unknown, the subject should understand that it is unrealistic to expect identification of *all* possible risks; nonetheless, he should be reassured that any research procedure which involves risk to the participant has been carefully pretested.

Use of data

While it is desirable that subjects be informed of the uses to which any of the data collected will be put, we recognize that in the case of questionnaires deposited in a data bank often no single purpose can be specified, as they may later be used in the analysis of problems unrelated to the original reasons for the data collection. The precautions initially taken to ensure anonymity of responses may make it impossible to locate the participants a second time to obtain their informed consent to a new analysis of the data. This should be explained to participants and a general consent obtained to re-use data with a guarantee of anonymity.

Coercion and remuneration

Informed consent must be freely and explicitly given, without any form of coercion, constraint or undue inducement. It is accepted that subjects may be remunerated for the time they give to participating in a project, and that this remuneration may take into consideration the trouble or inconvenience which their participation involves. However other more subtle forms of inducement, such as higher marks or favourable publicity, are not permissible. And remuneration ought never to be such as to lead a subject to ignore the risks involved in participation. Moreover, potential subjects should always be advised that they may withdraw from the project at any time.

There is an obligation to make the results of research available to the subjects. This can be accomplished by providing one or more copies of publications to any organization involved in the research (for example, a Band council) or to the local public library and to key individuals who aided in the research.

Written consent

It may not always be possible to obtain written consent, but in cases where this is not done, the researcher should be required to describe the procedures used to obtain consent and to give satisfactory reasons for not obtaining written consent.

Consent form

The consent form itself is the tangible evidence of an act of voluntary cooperation between the researcher and his subject, based on the subject's understanding of what is implied in the consent. It is, in effect, a contract, and its purpose is the protection of both the subject and the researcher and no less the sponsoring institution and community as a whole.

The form of consent should set out:

- 1) the purpose of the research;
- 2) the benefits envisaged;
- 3) any inconveniences involved;
- 4) the tasks to be performed;
- 5) the rights of the subject, i.e., the right to withdraw at any time without penalty, the right to confidentiality of personal information;
- 6) any departures from normal practice being planned by the researcher;
- 7) the risks involved;
- 8) the name of the person, group or institution eliciting or receiving the consent.

The wording of the consent form should be as similar as possible to the verbal description given to the subject. The form should provide for hearing any complaint the subject may subsequently have.

Summary

We would emphasize that those participating in a research project should never, either before or after the experiment, have any reason for saying that they did not fully understand what was involved. Moreover, while consent alone is never sufficient to justify research involving humans, it is a prerequisite to carrying it out.

It is understood that in working in the field outside one's own culture, fully informed consent may be impossible to obtain. In such circumstances, extra care should be taken by the researcher to protect the interests of participants and third parties in the research. Moreover, in field research consent should always be obtained from the appropriate authorities for the use and relocation of objects belonging to the community under study.¹

Recommendations

We urge the adoption of the following guidelines on informed consent:

- 1) that with due concern for the limitations of their comprehension, potential participants be given a full and fair explanation of the purpose of the research and the procedures to be followed, together with a careful estimate of the risks and benefits;
- 2) that no coercion or other form of undue financial or other inducement be used to obtain subject participation;
- 3) that it be made clear to participants that they may withdraw their participation at any time, just as the investigator may conclude his research at his own discretion in the interest of the subjects, the project or himself;
- 4) that, where practical, informed consent of both parents and children always be obtained in respect of research involving children;²
- 5) that special precautions be taken to protect captive populations from being coerced into participation;³
- 6) that participants be explicitly assured of confidentiality;
- 7) that participants be apprised of their rights to inquire about the research, and that whenever practicable they have recourse to a knowledgeable resource person outside the research group for that purpose;
- 8) that informed consent always be obtained in writing and where this is not possible, that the procedures to be used in obtaining consent be clearly described and open to examination.

2. Deception

Arguments against using deception

An issue very closely related to informed consent is deception, to which we are strongly opposed. We define deception as the intentional misleading of subjects to believe that the procedures and purposes of a research project are not what they actually are. Getting the confidence of a person and then using him for purposes that are concealed from him may well be an infringement

of human dignity. Drawing a subject into participation in this way amounts to false pretenses. If done for gain at the subject's expense, it would be a criminal offense. Moreover, the investigator has the enormous prestige of scientific research behind him, as well as the implicit support of a university or research institute, and the subject is thus in a very vulnerable position in relation to the researcher. Conscious of this, a participant may be correspondingly hostile or distressed when he learns that he has been led up the garden path. Permanent deception is almost impossible to maintain; the truth tends to come out over time, and in the process, research generally is likely to come into disrepute, making it more difficult to find persons who are willing to participate. Thus, for reasons of principle and practice, deception should be avoided.

Methodology
requiring use of
deception

Deception of subjects as to the purpose of the research is often claimed to be indispensable to the methodology being employed, and therefore justifiable. We urge that before a particular methodology is decided upon, consideration be given to the kind of deception to be used and its relationship to the importance of the expected results, for the use of deception is not justified unless there is evidence that a significant scientific advance could result from the research. We believe, moreover, that the researcher should be required to demonstrate that an alternative methodology would not be feasible.

If it is considered absolutely necessary to employ deception, the researcher must be able to demonstrate that nothing is being withheld which if made known would cause the subject to refuse to participate. He should, in addition, be able to demonstrate that his proposed deception will not result in harm to the participants or make them feel that they have been trapped into divulging aspects of their personality they would not want to reveal.

Debriefing

On those rare occasions where deception can be justified, subjects should be debriefed at the earliest possible moment and told of the reasons why deception was necessary. This policy should likewise apply where others in authority have given their consent, although before employing deception in such cases, the researcher should weigh the potential damage to the trust relationship between the person in authority and his ward when the deception is revealed.

A fortiori deception should never be permitted where there is no provision for debriefing.

Deception should never be permitted if there is any risk of harm to the subject. Nor should it be permitted unless the researchers are known to be mature scholars who will be supervising properly-trained assistants.

Reaction of public

Finally, it is important for the research community to be aware of the strong public reaction against deception even though carried out for laudable purposes. Research is almost always undertaken at public expense, and in common with other expenditures, is coming under closer public scrutiny than ever before. So the more speculative and recondite the aims of the research, the less the justification for permitting deception.

Recommendations

We urge the adoption of the following guidelines in respect of the use of deception:

- 1) that deception never be permitted when there is any risk of harm to the subject or when debriefing is not possible;
- 2) that if deception is claimed to be indispensable to the methodology, the researcher be required to show that no other methodology would suffice and evidence be shown that significant scientific advance could result from the research, before the deception is considered justifiable;
- 3) that if deception is to be used, the researcher be able to show that nothing has been withheld from the subject which might, if divulged, have caused him to refuse to participate;
- 4) that when deception is employed, debriefing take place as soon as possible.

3. Risk/Benefit

We believe that benefits do not necessarily justify risk of potential harm to subjects. The elements of risk and benefit should be assessed separately and potential harm always be minimal and reversible.

Difficulties in
assessment

The problem of establishing an acceptable risk/benefit ratio in non-medical research is extremely difficult to resolve, especially in view of the lack of precise definitions of risk and benefit. A great deal of research is

carried out with public sanction in the interests of the advancement of science. There is however a certain threshold of risk beyond which no presumed or probable benefit can justify carrying out the research.

Therapeutic/non-
therapeutic research

Complicating the difficulty of trying to assess risk/benefit is the need to differentiate for the purpose between therapeutic and non-therapeutic research. The former is best illustrated in the doctor-patient tradition where the primary concern has long been accepted as the welfare of the individual patient. In non-therapeutic research however the primary concern is the advancement of knowledge, and there is a minimal, if any, immediate benefit to the subjects themselves. Thus the public cannot be expected to sanction self-monitoring by those carrying out non-therapeutic research, for there might be, on the part of the latter, a tendency to overestimate the prospective benefits to science of the research and to underestimate the risk to subjects.

Unforeseeable risks

A further problem in applying the risk/benefit factor is that both risks and benefits may be unforeseeable as well as unforeseen. And not infrequently, no immediate benefits may be expected to accrue from the proposed research.

Unforeseen damage

The ever-present possibility of unforeseen damage being done in a research project emphasizes the desirability of a review committee making a prior assessment of the skill and sensitivity of the researcher, which could well affect the potential risk to his subjects.

Behavioural change

Except where there is clear foreseeable benefit to the participant, such as might conceivably be the case in therapeutic research, the researcher has no right to attempt to make what may well turn out to be long-term changes in a person's behaviour or attitudes.

Where the researcher plans to induce short-term behavioural changes, permission for a project to proceed should be dependent upon assurances as to their reversibility.

Psychological
damage

We realize that psychological damage may take many forms: loss of dignity or self-esteem, social embarrassment, generation of guilt or remorse or of feelings of being exploited or degraded. It is not always easy to assess potential damage of this kind, but we recommend

that the maxim be adopted that the more incalculable the damage, the more cautious should be the researcher and the review committee. The burden of proof must rest with the researcher to demonstrate the harmlessness of his proposal. At a later stage, he must ensure that publication of the results preserves the anonymity and integrity of the participants.

Vulnerable
populations

Certain populations are particularly vulnerable to damage as research subjects for varying reasons such as age, limited mental capacity or psychological disposition. It is therefore important for both the researcher and the review committee to pay close attention, in assessing risks, to the nature of the target population and to err on the side of exaggerating the risk if the subjects are known to be particularly vulnerable.

Risk to cultural and
proprietary values

While risk is normally associated with physical, psychological and humane values, it is well to remember that cultural and proprietary values may also be adversely affected in carrying out research. Particularly in archaeological and anthropological research, it is all too easy to commit ethnographic inaccuracies or discourtesies in exhibiting artifacts and sacred material or removing artifacts relating or belonging to the host community.

Third-party risk

The problem of third-party risk will be discussed later with reference to the issues specific to research on cultures outside one's own.⁴ However, we would emphasize here that third-party risk is by no means restricted to a single type of research. In verbally or visually transmitting findings on individuals or groups who have participated in a project, the researcher must therefore be careful not to put at risk, through cultural, social or political embarrassment, others who may be identified with his subjects. It is thus vital that investigators consider in advance the potential effects of the research and reports resulting from it on the population or subgroup from which participants are drawn.

Early monitoring

By its exploratory nature, research always involves the unforeseen. One would be remiss, therefore, having taken every reasonable precaution and carefully scrutinized the ethical aspect of a research project involving human

subjects, to drop all concern after the project has been put into action. We believe that once the research is underway, early monitoring procedures should be employed to uncover any inherent unforeseen risks which may justify its immediate termination.

Summary

We would reiterate that in assessing the risks and benefits of research, fuller consideration should be given to the risks to physical, psychological, humane, proprietary and cultural values than to the potential contribution of the research to knowledge, although the latter should always be borne in mind.

Recommendations

We urge the adoption of the following guidelines in respect of risk/benefit:

- 1) that the more incalculable the risk, the more cautious should be the researcher and the review committee in permitting the project to be carried out;
- 2) that where procedures involve risk, the researcher have first-hand experience with these or similar procedures and have previously carried them out successfully, at least under supervision, without detriment to the subjects involved;
- 3) that before being permitted to proceed, the researcher be able to show that any behavioural changes will be reversible;
- 4) that, in assessing risks, the nature of the target population be taken into consideration;
- 5) that the researcher be able to demonstrate that he has adopted satisfactory measures to guard against third-party risks;
- 6) that early monitoring procedures be provided for, so that unforeseen damage can be remedied without delay or the research promptly terminated;
- 7) that the onus fall squarely on the researcher to avoid hazards to subjects, either in carrying out the research or through subsequent publication of its results, particularly where no immediate benefits can be foreseen;
- 8) that the burden of proof rest with the researcher to show that he has taken steps to minimize risks to subjects.

4. Privacy

Definition of right to privacy

The right to privacy provides for the deeply-felt need of human beings to reveal to others only those aspects of their lives which they wish to reveal. It extends to all information relating to their physical and mental condition, their personal circumstances and social relationships which is not already in the public domain. It gives to the individual or collectivity the freedom to decide for themselves when and where, in what circumstances and to what extent their personal attitudes, opinions, habits, eccentricities, doubts and fears are to be communicated to or withheld from others. The right to privacy thus represents a very significant aspect of human freedom, and as such, will very often be in direct conflict with the community's or society's search for knowledge.

Threats to privacy

Sensitivity concerning personal privacy has understandably increased with the growth of threats to it. One-way mirrors, portable microphones and taperecorders, computers, miniature cameras and many other technical devices are all formidable threats to privacy, and we are well aware that behavioural research is only one area in which they are employed. However our present task is to emphasize the importance of reconciling the needs of scientific research with the protection of individual and collective rights, and it would seem that the only way of accomplishing this is by obtaining fully informed consent from potential subjects, whether they be individuals, organizations or communities. It therefore becomes important to determine what constitutes invasion of privacy.

Invasion of privacy

Invasion of privacy can be divided into two general categories: invasion of the private personality and observation of behaviour in private settings.

We have confirmed our view that to probe private aspects of the human personality without consent is an infringement of an important individual right. But when the subject consents to participate in such research, by responding to a survey questionnaire or fulfilling certain tasks for the investigator's observation, an invasion of privacy cannot be claimed.

In giving consent, the subject must be fully informed of the nature of the information the investigator is seeking, especially in the case of research instruments designed to

have the subject unwittingly reveal characteristics which he would not wish to share had he known the researcher's intention. Administration of questionnaires designed to reveal aspects of a subject's personality without informing him of the type of information sought is nothing less than deception and should be treated according to the guidelines set out under that heading.

Public settings

Observation of crowds in public settings cannot be considered an invasion of privacy. The ethical issues involved are related to anonymity and they are discussed under confidentiality and anonymity.⁵ The observation of an individual in private settings is a different matter. Following a person to keep track of his movements, observing him covertly, eavesdropping on his conversations, if persisted in, are not only invasions of privacy but verge on besetting, which is also illegal.

Private settings

Other examples of
invasion of privacy

Other examples of invasion of privacy would be attempts to obtain descriptions, either oral or written, of one person from another, such as information elicited from children about their parents' life-style.

Use of the above techniques need not, however, lead to violation of privacy if prior consent is obtained and if anonymity and confidentiality are guaranteed. But the extent to which interference with personal privacy can be justified should always be looked at in the light of the urgency of carrying out the research and of the need to identify participants or otherwise put them at risk. It must also be borne in mind that concepts of privacy should be viewed in relation to the mores of the individuals or groups under study, rather than from the point of view of the researcher. In general terms, a reliable guide for the researcher is that he not violate the expectations of subjects as to invasion of privacy.

Recommendations

We suggest the following guidelines in respect of privacy:

- 1) that if there is to be a probing of private personality or private affairs the intention to do so be made explicit, and where there is an implication or promise of protection of privacy, the protection be more generous than the promise;
- 2) that informed consent be obtained from those to be observed or studied in private settings;

3) that since concepts of privacy vary from culture to culture, the question of invasion of privacy be looked at from the point of view of those being studied rather than that of the researcher;

5. Confidentiality and Anonymity

When people agree to divulge personal information about themselves or the collectivity to which they belong, it is on the understanding that such information will be regarded as confidential, unless the investigator makes an explicit statement to the contrary and subjects agree.

Anonymity of subjects

Confidentiality involves a clear understanding between the investigator and respondents as to the original use to be made of the data and their deposit for possible re-use. Names and any other identification must be removed from questionnaires, tapes or other documentation so that the information they contain cannot be traced back to the source. Confidentiality also requires that researchers be scrupulous when publishing research results in preserving the anonymity of subjects, whether they be individuals or institutions, unless consent has been given to reveal their identity. In this connection researchers must ensure that unusual response combinations do not unwittingly reveal the identity of respondents and that individuals giving information with respect to their group, tribe or community cannot be identified.

Risks to anonymity

The researcher should remember that a wide variety of information can identify a subject. In the case of written information, this may be the subject's name, of course, but also his address, social insurance number or telephone number. In taperecordings or videotapes, a person may be identified by voice or appearance. When a subject is described as a member of a small group, the smaller the group, the more stringent the need to protect his identity.

Observation in public settings

It is not usually possible to inform those being observed in public settings that they are involved in a study of crowd behaviour. However, problems related to anonymity can arise if individuals are identifiable in close-up photographs, or if they are identified in a caption beneath a photograph. It therefore becomes extremely important for those involved in this type of research to take care to preserve the anonymity of 'participants', or if for some reason this is not possible, to present reasons

why divulgence will not be harmful to those photographed or the group they represent. The same caution applies to the use of unobtrusive recording mechanisms in public situations; the anonymity of those being implicated must be preserved. Researchers involved in research where these issues arise would be well advised to familiarize themselves with the appropriate provincial privacy acts.

The use of institutional records without the informed consent of the person documented can easily lead to breaches of confidentiality and anonymity. The researcher should demonstrate the procedure he will follow in order to ensure confidentiality and anonymity. For example, he might be in a position to assure the review committee that collaborators examining the records would be unlikely to know or have contact with the people whose records were being examined.

Third-party risk

It is the researcher's obligation to consider the effects of his techniques and publications on the larger population to which his subjects belong.

Public safety and legal liability

If confidentiality or anonymity cannot be guaranteed because of the nature of the research, participants should be made aware of this limitation and its possible consequences before becoming involved in the research. This situation may arise, for instance, where questions of public safety or legal liability are concerned. If a research project revealed that a particular combination of circumstances created hazardous stress conditions in certain airline pilots, it would be highly undesirable that their identities be kept confidential by the researchers. Where the researcher is in doubt about the need to divulge information involving public safety, and to whom the information should be conveyed, he should consult with colleagues or with the review committee.

Recommendations

We suggest the following guidelines in respect of confidentiality and anonymity:

1) that there be a clear understanding between the investigator and respondents that the identity of respondents and the information they divulge will be kept confidential in both the original use of data and in its deposit for future use;

- 2) that unless there is an explicit statement by the researcher to the contrary, to which the subject agrees, it be understood that personal information given by the subject will be regarded as confidential and that the researcher will explain the steps to be taken to ensure that confidentiality and anonymity will be maintained;
- 3) that if confidentiality or anonymity cannot be guaranteed, participants be made aware of this limitation and its possible consequences before becoming involved in the research;
- 4) that the anonymity of subjects be protected against indirect or unwitting disclosure by association or combination of information;
- 5) that the researcher has an obligation in terms of third-party risk.

Special Applications of Ethical Principles

1. Research in the Humanities

As already mentioned, research ethics are not restricted to particular disciplines or methodologies but are involved wherever an investigator intervenes in the lives of others. The scholar in the humanities as well as in the social sciences should therefore be alerted to the possibility of ethical conflict in his work. Historical investigation may pose problems of confidentiality or invasion of privacy if living persons are likely to be affected by the publication of private materials. The biographer, particularly of a living person, whether the interest be artistic or historical, must exercise care not to infringe on the rights of his subject.

Researchers should be careful in purchasing and taking out of the country original manuscripts that they are not unwittingly or without permission depriving another country of what may be a national treasure.

Copyright

Those writing history, biography or artistic criticism should be aware that the rights to private papers, photographs or artistic productions are protected through copyright, regardless of whether such material resides in an archive, gallery or museum. One cannot legally consult, cite, reproduce, publish, refer to or distribute such documents or articles without first obtaining permission, either from the author or his heirs or from any other person or institution given copyright ownership by the author.

2. Research in Anthropology and Archaeology

Recommendations for
acquisition of cultural
properties

*Acquisition and
safekeeping of
cultural properties*

The term 'cultural' property⁶ means property which, on religious or secular grounds, is specifically designated as being of importance for archaeology, prehistory, history, literature, art or science.

We recommend the following guidelines for the acquisition and use of cultural properties for the purposes of research or exhibition. The procedures should apply when the acquisition is facilitated or financed in part by research grants or other public funds.

- 1) All acquisitions should be for the purpose of scholarship and not for personal gain, private collection or sale.
- 2) In all acquisitions the legal requirements of the country of origin must be strictly observed.
- 3) Where there is doubt as to the legal ownership of the objects, the researcher acquires them at his own risk and must immediately inform the proper authorities of the country concerned. If the acquisition is not approved, the researcher should return the object to those authorities.
- 4) The researcher should not accept or otherwise acquire objects unless proper storage, protection and preservation of the objects can be provided.
- 5) The person acquiring the objects should take all necessary precautions for their security and safekeeping.
- 6) Materials collected should be properly catalogued, providing a description of the objects or documents and their provenance, and this catalogue made part of the public record.
- 7) After a reasonable time the objects or documents should be made accessible to other scholars who have legitimate research interests in them.

Deaccessioning

- 8) If objects or documents are to be deaccessioned or discarded after use, they should first be offered to the appropriate public authorities or educational institutions in the country or district of origin.
- 9) If such an offer is refused or cannot be made, the objects to be deaccessioned should be offered to other educational institutions in Canada where they could be put to proper use or be preserved for future generations.
- 10) If any of the objects or documents are to be deaccessioned or discarded after examination, they should never be traded or sold to private individuals or to dealers, but always remain available in the public domain.

Reproductions

11) All copies or reproductions of objects collected, whether for exhibition or distribution, should be clearly marked as copies.

Exhibition and publication

12) Objects should not be publicly exhibited, discussed or published so as to cause embarrassment to the individuals, groups or countries represented by or associated with the objects or documents in question.

13) Objects or documents should not be exhibited in ways that are likely to damage or destroy them.

**3. Research on
Captive
Populations**

Another area we believe to be of great sensitivity is research on captive populations, which we define as individuals or groups who are in a relationship with others involving a power differential which could operate to their disadvantage as subjects. Thus minors, prisoners, students, employees, minority groups, incapacitated people and the socially deprived might well be involved.

Coercion

The problem here is one of ensuring that consent is not in some way or to some degree the result of coercion. We do not consider the consent of a person in authority to constitute informed consent of subjects in subordinate positions. Consent of the subjects themselves should always be obtained. To ensure that consent is not gained through subtle pressures being brought to bear on captive subjects, it would seem prudent for institutional committees reviewing projects to seek advice from someone with special expertise as to the forces likely to be operating on the captive group, such as how records are kept on them and how they are rewarded or penalized. There should, for instance, be no interference with prisoners which involves any risk or disrespect or encroaches upon the individual's fundamental rights. For if a prisoner sees his cooperation in an experiment as a means of improving his lot, the direct or indirect pressure implied in this situation invalidates the consent.

**Independent
advocate**

Where consent of the subjects themselves cannot be obtained, consent must be sought from someone in authority, together with written consent from an impartial person who may act as an independent advocate. As a further protection, we recommend that captive populations always have the power of veto over their participation in a research project.

Recommendations

We recommend with respect to captive populations:

- 1) that, in addition to consent of the authorities, the consent of the subjects themselves always be obtained;
- 2) that, where it is not possible to obtain the informed consent of the subjects, the written consent of an impartial person be obtained, in addition to the consent of the authorities;
- 3) that captive subjects always have the right and power to veto consent given by the authorities or an impartial person for their participation in the research;
- 4) that special care be taken with respect to all other ethical principles where captive populations are involved.

4. Research on
Children

In view of the possibility of long-range harm, because of their age, developmental and psychological processes and the problems associated with gaining their informed consent, we are especially concerned about ethical practices in research on children. Ideally, we should like to have advocated that only research producing results which would be directly beneficial to the children involved should be carried out. But the fact is that, despite the possible overall benefits, most research has minimal, if any, immediate or direct benefit to those involved in the study. This situation imposes a very heavy burden of responsibility in the case of research on children, particularly where behavioural manipulation is involved. Accordingly, we feel that the following safety measures are in order in addition to those stated elsewhere in this report. The informed consent of parents should always be obtained for research with minors. In the rare cases where the precise purpose of the research cannot be divulged to the parents in case they might try to influence the child's performance, they should *always* be told of the procedures to which their child will be subjected. Despite the informed consent of parents, we believe that any individual child should be able to refuse to participate in the research study or to withdraw his participation at his own request.

Consent

Precautions

As an extra precaution, institutional review committees should not hesitate to seek expert advice on the potential short- or long-term risks in a proposed research project with children if they themselves do not feel competent to make such judgments. Moreover, we believe that once the

Early Monitoring	research is underway, early monitoring procedures are important, especially in educational research where experiments are being carried out with children in learning environments.
Recommendations	<p>We urge the adoption of the following guidelines in respect of research on children:</p> <ol style="list-style-type: none">1) that the informed consent of parents always be obtained before experimenting with minors;2) that, in the rare cases where the precise purpose of the research cannot be divulged to the parents, they always be told of the procedures to which their child will be subjected;3) that each individual child be given the opportunity to refuse to participate in the research or withdraw his participation at his own request;4) that review committees seek expert advice, whenever necessary, on potential short- or long-term risks to children;5) that early monitoring procedures be employed to uncover any unforeseen risks in research involving children.

Research on Cultures, Countries and Ethnic Groups Different from One's Own

It is important to understand that such research requires a somewhat different application of ethical principles from that which is used by the researcher operating within his own culture, country and language. The researcher in the field has no alternative but to give an account of himself that is credible and acceptable to the people among whom he is working, and which is in accord with the role they will see him carrying out. To gain their trust and cooperation he may tell them that he has come to learn about their way of life, languages, customs and beliefs. But the problems of communicating to people of different cultures exactly what uses will be made of the information they provide may be insurmountable.

Informed consent	This communication gap, wherever it occurs, may make fully informed consent impossible to obtain, especially as the people under study may be unable to estimate the extent of the risks to their own well-being and reputations, to say nothing of potential damage to the dignity and sensitivity of their descendants. To add to the
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problem, in field work abroad, individual consent of any kind may sometimes not be feasible, and there may not be any person in a particular collectivity with authority to give formal consent. Any such absence of fully informed consent, rather than giving him more license, places additional responsibility and restrictions on the researcher. We recognize that it may not be feasible to consult an independent advocate. Accordingly, we believe the researcher should be required to satisfy the review committee concerning the safeguards he has built into his methodology to protect his subjects.

Remuneration

It is accepted that subjects may be remunerated for the time they give to participating in a project, and that this remuneration may take into consideration the trouble or inconvenience their participation involves. In anthropological field work, reciprocity rather than payment is normal and desirable in some regions for certain persons. Reciprocity may take the form of gifts, loans, transportation and other services.

Deception

Since he is best able to foresee the consequences of his work, it is important that the researcher attempt to forestall dangers to his subjects or to the population they represent. Indeed, if the dangers can be foreseen but not forestalled, it is highly questionable whether the research should be undertaken. Above all, intentions and risks must not be deliberately concealed for the purposes of obtaining cooperation.

Privacy and
confidentiality

The researcher working outside his own culture must also bear in mind that in some societies, privacy and confidentiality may apply to quite unexpected kinds of activity. Certain ceremonies may be considered the privilege of a particular class or aggregate of individuals: men may not view ceremonies of women, or youth may not be a party to deliberations of the elders. We would therefore re-emphasize here our previously stated principle that concepts of privacy always be viewed from the perspective of the research subject or the subject's culture rather than from that of the investigator.

Publication

Whenever, as is often the case, the researcher outside his own culture is operating from a position of advantage, he has particularly heavy responsibilities to his subjects insofar as publication is concerned. Margaret Mead sums these up succinctly: "There is first of all the responsibility

to individuals who, if identified, must not thereby be exposed to legal sanctions, to ridicule or to danger. Second there is the responsibility to the group as a whole. Where customs are portrayed that contrast with the ethical standards of those who govern them or with the missionized or educated members of their own society, these must be represented in such a way that full justice is done to the cultural framework within which a given practice, however apparently abhorrent, occurs. . . . Finally, there is the responsibility of the anthropologist for the way in which his findings are interpreted and articulated into the ongoing understanding of human behaviour in the human sciences of his day.’⁷

Research in other countries

In the cause of developing and maintaining good international scholarly relations, it is essential that Canadian scholars (faculty and graduate students) fully appreciate the ethics involved in conducting research in other countries as well as the legal requirements of such research in certain countries. The ‘foreign researcher’ must be seen in the context of changing social, economic and political relations as, for example, between the developed and developing countries. Today, even under the best conditions, the foreign researcher may merely be tolerated as one of many visiting professors, volunteers and technical assistants. For this reason the Canada Council now requires that all applicants provide proof of their personal acceptability and that of their research program to the other country or countries concerned.

We add our approval to the further requirement that grantees show how they intend to meet the following commitments:

- 1) to involve local students and researchers in as many ways as possible;
- 2) to give lectures and seminars not only in universities, but also in government departments and local schools;
- 3) to contact local Canadian authorities so that they are fully aware of the research program and objectives;
- 4) to be reasonably proficient in local languages or dialects;
- 5) to attend meetings of local or regional learned societies for the presentation of papers based on research findings;
- 6) to make available to the host community any data which may be of benefit or interest to its members.

Research in Canada

We also note that researchers intending to carry out field work in Canada are required to obtain permission from the appropriate authority and are asked wherever practicable to make their findings available to the host community.

**Institutional
Review
Committee**

Responsibility to the
community

We have expressed earlier our conviction that the university must accept its responsibility to the community to which it belongs for the research projects it permits to go forward to the Canada Council. We believe this can be practised through the use of institutional review committees. Moreover, since the university is a part of the community, and ethical issues related to research involving human subjects have a political as well as a professional element, we emphasize the need to sound out the general opinion of the community concerning the ethical acceptability of particular research projects. This might be done by engaging consultants or adding ad hoc members to the committee as appropriate.

Pre-screening of
applications

We recommend that, where research involves the interests and legitimate concerns of human subjects, approval of the appropriate institutional review committee should be a pre-requisite to the award of a Research or Negotiated Grant or Leave Fellowship.

Nature and
composition of
committees

We recommend that the institutional review bodies be standing committees, with perhaps sub-committees in the large universities, to which persons may be added on an ad hoc basis as required by the nature of the applications to be reviewed. The review committee should be broadly based and include representatives both from inside and outside the department and discipline in question. We would advise that institutional review committees seek legal advice where needed.

Protection of the
researcher

Concern has been expressed to us that the establishment of such review committees might place power in their hands which could be used to the detriment of an individual researcher's career. We would therefore urge that those responsible for setting up review committees see to it that such an injustice to the researcher be prevented. Control of a reviewing body in any individual case should not be left to those in a decision-making position with regard to the researcher's tenure, promotion or salary, or to persons who are competing for prestige

and position in the same department as the applicant. As committees intended to determine the ethical acceptability of any project, these groups should protect the 'rights' of both subject and researcher.

Dissent

It is, of course, desirable for a review committee to achieve consensus, but where there is a strong minority objection, the dissent should be recorded and transmitted to the Canada Council.

Appeal

Provision should be made for the applicant himself to be present for the review of his project if the screening procedures reveal that it is ethically questionable, to give him the opportunity to adjust his proposal to meet ethical requirements. If he cannot make satisfactory adjustments, he should be able to appeal; if his project is ultimately rejected on appeal, the applicant should be advised in writing of the reasons for rejection.

While we would encourage as much openness as possible in the review process, we hold that in cases of appeal, review committee members have a right to privacy concerning the personal opinions they may express about the ethical nature of a research proposal. However, we are of the opinion that they should collectively be prepared to divulge the precise reasons for adverse decisions, for we believe it to be important that the review procedures be seen as just and reasonable.

Early monitoring
procedures

Review in and of itself is no guarantee of ethical research conduct. It is therefore vital to monitor projects to see whether principle and practice coincide. We realize however that monitoring every approved research project may be impossible for a review committee, especially in the larger universities where many research projects are undertaken. In these cases monitoring should be conducted on a selective basis at the discretion of the committee.

Monitoring becomes especially important in cases where the research is sensitive in nature for any of the following reasons:

- 1) the potential for harm to the subjects;
- 2) the methodology being employed;
- 3) the nature of the target population;
- 4) the subject-matter of the research;

5) the presence of a delicate balance between risk and benefit.

In such cases, the review committee may wish to ask for a progress report after a reasonable period of time, so that the research may be terminated or the research design modified, should experience indicate that unforeseen problems are arising.

Possible methods

The form that the early monitoring should take will vary according to the nature of the research project. In the case of an experiment, it may be possible simply to observe the experimental procedure. In other cases an interview with the researcher or another person close to the project, such as a school teacher or parent, might serve the purpose. The review committee might in certain cases require a progress report after a reasonable period of time mutually arranged by the committee and researcher, and in all cases, any significant change in research design must be reported to the committee.

Recommendations

We urge the adoption of the following guidelines in respect of early monitoring procedures:

- 1) that all research projects involving children be assessed in terms of the need for some form of monitoring;
- 2) that every project with a likelihood of unforeseen risks (as previously defined) be assessed in terms of the need for some form of monitoring.

Publicizing review
committee approval

Careful consideration has been given to the question of publicizing institutional review committee approval when advertising for participants in research projects. We find this practice to be undesirable in that it may serve as undue inducement to potential subjects, perhaps persuading them that what is to be investigated carries no risk at all, whereas no guarantee to that effect can be given. Advertising university endorsement of the research proposal without full disclosure of the protocol and the circumstances of its ethical review could be misleading, and could jeopardize the reputation and legal position of the university. We therefore recommend that this method not be used for recruiting potential subjects for research. However, we also recognize the researcher's right to personally inform potential subjects that his project has been scrutinized and approved by an ethics review committee of the university.

III Concluding Comments

It is apparent from the foregoing that we do not believe any set of hard and fast rules would offer useful solutions to ethical problems which arise essentially out of a conflict of values, and which are diverse and often unforeseeable in the concrete form they take. We have therefore tried to isolate and analyse, for the benefit of the researcher, the important ethical issues surrounding research involving the interests and legitimate concerns of human subjects and to offer some guidelines to the universities as to the role and composition of review committees which should screen applications before they are forwarded to the Canada Council. It is hoped at the same time that in a more general way this document will heighten sensitivity to and stimulate discussion of ethical issues within the academic community. For we believe a large measure of judgment and discretion to be needed on the part of the researcher himself, to the point where in certain circumstances, he should make the decision to abandon his research plans because the demands of ethical research cannot be reconciled with his need for direct access to and use of certain information or data. Only through the personal exercise of such discretion can research be conducted so as to maintain the integrity of the research enterprise without reducing the potential for conducting research in the future.

IV Notes

1. See page 20 for a more complete statement.
2. See page 22.
3. See page 21.
4. See page 23.
5. See page 17.
6. We quote from the definition used by Unesco, reproduced as an appendix.
7. Margaret Mead, 'Research with Human Beings: A Model Derived from Anthropological Field Practice', in *Ethical Aspects of Experimentation with Human Subjects*, ed. Paul A. Freund (Cambridge: Daedalus, 1969).

V Appendix

Article 1, *Record of General Conference 16th Session*, Unesco
12 October — 14 November 1970, Paris
Volume 1, Resolutions, pp. 135-141
Unesco, Paris, 1971

For the purposes of this Convention, the term 'cultural property' means property which, on religious or secular grounds, is specifically designated by each State as being of importance for archaeology, prehistory, history, literature, art or science and which belongs to the following categories:

- a) Rare collections and specimens of fauna, flora, minerals and anatomy, and objects of palaeontological interest;
- b) property relating to history, including the history of science and technology and military and social history, to the life of national leaders, thinkers, scientists and artists and to events of national importance;
- c) products of archaeological excavations (including regular and clandestine) or of archaeological discoveries;
- d) elements of artistic or historical monuments or archaeological sites which have been dismembered;
- e) antiquities more than one hundred years old, such as inscriptions, coins and engraved seals;
- f) objects of ethnological interest;
- g) property of artistic interest, such as:
 - i) pictures, paintings and drawings produced entirely by hand on any support and in any material (excluding industrial designs and manufactured articles decorated by hand);
 - ii) original works of statuary art and sculpture in any material;
 - iii) original engravings, prints and lithographs;
 - iv) original artistic assemblages and montages in any material;

- h) rare manuscripts and incunabula, old books, documents and publications of special interest (historical, artistic, scientific, literary, etc.) singly or in collections;
- i) postage, revenue and similar stamps, singly or in collections;
- j) archives, including sound, photographic and cinematographic archives;
- k) articles of furniture more than 100 years old and old musical instruments.

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The Institutional Guide to DHEW Policy on Protection of
Human Subjects, U.S. Department of Health, Education
and Welfare (1971)

Existing codes of ethics of Canadian universities as well
as those of professional associations in the humanities
and social sciences.



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